
Substantive and Procedural Principles of Decisionmaking for Incapacitated Patients

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Substantive Principles

As described in Chapter Two, there are two values that guide decisionmaking for competent patients: promoting patient welfare and respecting patient self-determination. They should also guide decisionmaking for incapacitated patients, though of necessity their implementation must differ. They are reflected, roughly speaking, in the two different standards that have traditionally guided decisionmaking for the incapacitated: “substituted judgment” and “best interests.” Although these standards are now used in health care situations, they have their origins in a different context—namely, the resolution of family disputes and decisions about the control of the property of legal incompetents. When people become seriously disabled and unable to manage their property, they may be judged incompetent and a guardian appointed to make financial and property decisions. These doctrines were developed to instruct guardians about the boundaries of their powers without issuing detailed and specific guidelines and to provide a standard for guidance of courts that must review decisions proposed by a guardian.¹

Simply stated, under the substituted judgment standard, the decisions made for an incapacitated person should attempt to arrive at the same choice the person would make if

¹ See generally Lawrence A. Frolik, *Plenary Guardianship: An Analysis, a Critique, and a Proposal for Reform*, 23 ARIZ. L. REV. 599 (1981).

competent to do so (but within boundaries of “reasonableness” intended to protect the incompetent).² Under the best interests standard, decisions are acceptable if they would promote the welfare of the hypothetical “average person” in the position of the incompetent, which may not be the same choice the individual would make (but which may still have some aspects of subjectivity to it).³

Despite the long legal history of both these standards, they provide only hazy guidance for decisionmaking even in their original contexts, not to mention in the often far more complex, urgent, and personal setting of health care. Although a number of recent cases involving decisions about health care for incapacitated patients have given courts the opportunity to clarify these often vague guidelines, increased confusion may have accompanied some of the attempts to add precision to these doctrines.

Substituted Judgment. The substituted judgment standard requires that the surrogate attempt to replicate faithfully the decision that the incapacitated person would make if he or she were able to make a choice. In so doing, the patient’s interest in achieving well-being as he or she defines it in accordance with personal values and goals, as well as the individual’s interest in self-determination, are both honored to the maximum extent possible, given the fundamental reality that the patient literally cannot make a contemporaneous choice. The surrogate’s decision is limited, however, by two general external constraints. First, the surrogate is circumscribed by the same limitations that society legitimately imposes on patients who are capable of deciding for themselves,⁴ such as not compromising public health (*e.g.*, by refusing a mandatory vaccination) or not taking steps contrary to the criminal law (*e.g.*, intentional maiming). Second, there are certain decisions that a patient might be permitted to make but that are outside the discretion of substitute decisionmaking and must therefore be decided by the standards of “reasonableness.” This is

² For example, the substituted judgment doctrine permits a surrogate to make a gift of some of an incompetent’s assets to a relative to whom the incompetent person had previously made gifts. The court will approve such a gift to the extent that it does not endanger funds needed for the incompetent’s support—even if the incompetent person would have been willing to be more generous.

³ The best interests doctrine has received most attention in law in cases involving questions of the custody and care of children, *see generally* 2 C.J.S. *Adoption of Persons* §§ 90-91 (1972), and in cases involving the expenditure of trust funds, *see generally* 76 AM. JUR. 2d, *Trusts* § 288 (1975), neither of which are entirely accurate guides to understanding how the standard ought to operate in instances of surrogate health care decisionmaking for adults who lack decisionmaking capacity.

⁴ *See* Chapter Two *supra*.

especially true for cases in which the decision risks imposing substantial harm on patients or depriving them of substantial benefit; people may volunteer for risky research with no direct therapeutic benefits to themselves but guardians may not enroll people in such research merely because it is known that, when they were competent, they believed that such research was very important. Thus even the essentially subjective substituted judgment standard is constrained by external limitations—that is, limitations not arising from the patient's own views.

For the substituted judgment standard to be employed there must be evidence of the patient's views, which could be derived from various sources. The surrogate may be guided in decisionmaking by prior directives expressly made by that patient governing the precise matter at issue. A person might, for instance, have clearly stated that he or she wished to avoid a potentially beneficial treatment that poses a risk of crippled mental faculties if there were another treatment available that, although promising more limited benefits, also poses substantially smaller risks of damaging the mind.

The substituted judgment standard is markedly simpler to use—and contains greater assurance of being faithfully implemented—when a competent individual has given clear directives regarding medical care in the event of incapacity, although such a directive does not necessarily resolve all problems.⁵ When directives are written rather than oral, it is more likely that the surrogate (or a third party who may report the incapacitated patient's putative directions to the surrogate) will not forget or misunderstand the patient's advance directives.

In the absence of advance directives, surrogates may be guided by the known values, goals, and desires of an incapacitated patient. It can reasonably be presumed, for example, that a person who is known to have had a particular aversion to painful medical interventions would wish to continue avoiding them if possible.

Best Interests. Decisionmaking guided by the best interests standard requires a surrogate to do what, from an objective standpoint, appears to promote a patient's good without reference to the patient's actual or supposed preferences. This does not mean the surrogate must choose the means the practitioner thinks is “best” for promoting the patient's well-being, but only a means reasonably likely to achieve that goal. Where, for example, there is more than one therapy available, a decision in favor of anyone of those considered appropriate by health care professionals will be acceptable under the best

⁵ See pp. 155-66 *supra*.

interests standard. However, the best interests standard would preclude the surrogate from choosing a therapy that is totally unacceptable by professional standards, even if the surrogate might choose that treatment for him- or herself. Fundamentally, the standard of “reasonableness” is inherently cautious.

In assessing whether a procedure or course of treatment would be in a patient’s best interests, the surrogate must take into account such factors as the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life sustained.⁶ An accurate assessment will encompass consideration of the satisfaction of present desires, the opportunities for future satisfactions, and the possibility of developing or regaining the capacity for self-determination.

The impact of a decision on an incapacitated patient’s loved ones may be taken into account in determining someone’s best interests, for most people do have an important interest in the well-being of their families or close associates. To avoid abuse, however, especially stringent standards of evidence should be required to support a claim that reasonable people would disregard their exclusively self-regarding interests (for example, in prolonging or avoiding suffering) in favor of their interest in avoiding psychological or financial burdens on the people to whom they were attached.

The Standard for Surrogate Decisionmaking. The Commission believes that decisionmaking for incapacitated patients ought, when possible, to be guided by the principle of substituted judgment, since it promotes the underlying values of self-determination and well-being better than the best interests standard does. However, the principle of substituted judgment cannot be employed universally; what some patients would want if competent cannot always be ascertained because of insufficient evidence about a patient’s values and preferences or because the patient’s cognitive abilities have always been so limited that he or she was never capable of developing or expressing preferences about the decision in question.⁷ When a patient’s likely decision is not known, the best interests standard presumes that the individual would

⁶ The phrase “quality of life” has been used in differing ways; sometimes it refers to the value that the continuation of life has for the patient, and other times to the value that others find in the continuation of the patient’s life, perhaps in terms of their estimates of the patient’s actual or potential productivity or social contribution. In applying the best interest principle, the Commission is concerned with the value of the patient’s life for the patient.

⁷ Allen E. Buchanan, *The Limits of Proxy Decision Making for Incompetents*, 29 UCLA L. REV. 393 (1981); John A. Robertson, *Legal Criteria for Orders Not to Resuscitate: A Response to Justice Liacos*, in A. Edward Doudera and J. Douglas Peters, eds., *LEGAL AND ETHICAL*

prefer what most reasonable people would want in similar circumstances. On certain points, of course, no consensus may exist about what “most reasonable people” would prefer. Furthermore, whenever a range of choices exists, even a best interests determination will display an element of subjectivity on the part of the surrogate in defining and weighing the patient’s interests.

To the extent feasible, efforts should be made with patients who are incapacitated though able to engage in communication to take into account their expressions of their own values and goals.⁸ Doing so will both promote their welfare as they understand and conceive of it and honor self-determination, though of an attenuated kind. When recovery of the capacity to make decisions is a reasonable possibility, enhancing its prospect should be another goal.

Procedures for Surrogate Decisionmaking

Regardless of the substantive principle used to guide decisionmaking for patients lacking decisional capacity, policies and procedures are needed for the selection and guidance of surrogate decisionmakers. Furthermore, there is a need to specify the circumstances under which review of the surrogate’s decision should be permitted or required and who should undertake such a review. The Commission recommends that however these problems are actually to be resolved, health care institutions should have clear policies about who has the authority and responsibility to determine incapacity, to speak for the patient, and to review determinations and decisions.

The Selection of a Surrogate. A sound policy for decisionmaking for incapacitated patients should take into account the urgency of the need to make a decision and the existence of suitable substitutes such as interested family members or a legal guardian.

ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS, AUPHA Press, Washington, D.C. (1982) at 159-63.

⁸ The only necessary implication of a determination of incapacity to decide about health care is that the patient’s decision, if any, may be overruled. Even if patients’ decisionmaking capacities are sufficiently impaired that it would be inappropriate to take their preferences as binding, patients may still be able to appreciate many aspects of the decision and may feel they have been treated more respectfully if those vested with the power to make decisions about them recognize the extent to which they are sentient beings with values and preferences of their own. Encouraging participation in the decisionmaking process may in fact facilitate recovery of capacity under some circumstances. These patients would be well served if their surrogates were to let them make such decisions for themselves, although the surrogate’s permission may also be required.

Emergencies. When a decision must be made immediately, in order to avoid seriously jeopardizing a patient's life or well-being, health care professionals are the proper decisionmakers.⁹ Since such emergency care is so often provided in institutional settings involving many practitioners, one aspect of a sound policy is having the means to assign decisionmaking authority to a particular member of the treatment team. This person should usually be the available professional who is most qualified to make the decision, according to the provider's estimate of the patient's best interests.

The line between emergency and nonemergency decisions will sometimes be hard to draw and will depend in part upon the type of facility and the ready availability of additional personnel for quick consultation. Institutional policy should minimize any tendency to overextend the exceptionally broad decisionmaking authority that genuine emergencies confer on practitioners. As soon as possible, without compromising the patient's well-being, other surrogates (such as family members) should be located, informed about the choices to be made, and involved in the decisionmaking.¹⁰

Nonemergency situations. In nonemergency situations, the proper presumption is that the family, defined to include closest relatives and intimate friends,¹¹ should make health care decisions for an incapacitated patient. There are several grounds for this stance:

- (1) The family is generally most concerned about the good of the patient.

9 Allen Buchanan, *Medical Paternalism or Legal Imperialism: Not the Only Alternatives for Handling Saikewicz-type Cases*, 5 LAW & MED. 97, 105-06 (1979); Alan Meisel, *The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 WIS. L. REV. 413, 476.

10 Meisel, *supra* note 9, at 476.

11 The Commission's broad use of the term "family" reflects a recognition of the fact that many of those with most knowledge and concern for the patient may not be his or her actual relatives. The fact that more than one person may fall within this category points to the need to designate one person as the principal decisionmaker for the incapacitated patient. One possibility is to define a presumptive priority, *e.g.*, that a person living with his or her spouse will speak for that spouse, that adult children will speak for elderly widowed parents, etc. In some cases such presumptions may be helpful. Nevertheless, the Commission believes that it is the responsibility of the practitioner to determine who acts as the patient's "surrogate." No neat formulas or serial orderings will suffice to capture the complexities involved in determining who among the individuals presenting themselves as friends and relatives of the patient knows the patient best and has his or her best interests in view. The responsibility is therefore on the practitioner either to determine who this spokesperson is or to go to court to have a guardian appointed.

- (2) The family will also usually be most knowledgeable about the patient's goals, preferences, and values.
- (3) The family deserves recognition as an important social unit that ought to be treated, within limits, as a single decisionmaker in matters that intimately affect its members.

Especially in a society in which many other traditional forms of community have been eroded, participation in a family is often an important dimension of personal fulfillment. Since a protected sphere of privacy and autonomy is required for the flourishing of this interpersonal union, institutions and the state should be reluctant to intrude, particularly regarding matters that are personal and on which there is a wide range of opinion in society.



The presumption that the family is the principal decisionmaker may be challenged for any of a number of reasons: decisional incapacity of family members, unresolvable disagreement among competent adult members of the family about the correct decision, evidence of physical or psychological abuse or neglect of the patient by the family, evidence of bias against the patient's interest due to conflicting interests, or evidence that the family intends to disregard the patient's advance directive or the patient's undistorted, stable values and preferences.¹² Even if, for one or more of these reasons, the family is disqualified from being the principal decisionmaker, it will often be appropriate to include family members in the decisionmaking process.

¹² Buchanan, *supra* note 9, at 111.

Nonemergency situations in which an incapacitated patient has no family but does have a court-appointed guardian raise special issues that are sometimes overlooked. The considerations that support a strong presumption in favor of the family's being the principal decisionmaker are weaker in the case of a court-appointed guardian, unless the guardian had been nominated by the patient prior to his or her incapacitation (in which case the guardian would be included in the definition of family used here).¹³ In the absence of disqualifying reasons, a guardian should act as health care decisionmaker since the person was already making the patient's other, nonhealth-related decisions. Through involvement in past decisionmaking, the guardian may have acquired a knowledge of the patient's beliefs, concerns, and values. Finally, in addition to the ethical grounds there are legal ones: the guardian has the sanction of court authority, which should reduce the concerns of practitioners that following this particular surrogate's decisions will expose them to civil liability.

If no family or legal guardian is initially available, a suitable surrogate decisionmaker should be designated to ensure a clear assignment of authority for decisionmaking and of responsibility for the exercise of this authority. Unless a suitable surrogate decisionmaker is identified, treatment decisions may lack continuity or may rest on an unclear foundation, making it difficult if not impossible to ensure that the process by which decisions are made is ethically and legally sound.

Review Procedures. Many people have "natural guardians" whose authority is either recognized as a matter of law (for example, parents deciding for children) or as a matter of custom (for example, one spouse deciding for the other).¹⁴ The decisions made by such surrogates are not routinely subjected to formal review. Such review is more likely to occur when very significant medical interventions are being contemplated, when disagreement arises between health professionals and surrogate decisionmakers, or when decisions are made by a guardian appointed by the court.

Formal review appears to be occurring with greater frequency; at the least, it is being more widely reported in the press. Review may be more frequent because of practitioners' growing sensitivity to the need to protect the interests of patients or because of their increased fear of legal liability, from which an advance ruling by a court could insulate them.¹⁵

¹³ If an incapacitated patient has both a competent family and a legal guardian, they should function together as principal decisionmakers to the extent permitted by local law.

¹⁴ See note 10, Chapter Eight *supra*.

¹⁵ See generally Robert A. Burt, *TAKING CARE OF STRANGERS*, The Free Press, New York (1979).

Although state law may require judicial review of certain decisions by a surrogate, well-conceived and carefully executed institutional guidelines may eliminate recourse to the courts that is unnecessary for adequate protection of patients' interests. Certainly, formal court proceedings on each and every health care determination would be unduly intrusive, slow, and costly and would frame treatment decisions in misleadingly adversarial terms.¹⁶

Judicial review. The most important kind of formal review at the moment is judicial. The justifications for turning to the courts are: (1) the state has a proper role, as *parens patriae*, in protecting the helpless, such as patients lacking health care decisionmaking capacity; (2) the authority of the state is legitimately exercised by courts in life-and-death matters, as in other important situations requiring individual decision; and (3) courts can reach appropriate judgments because of their expertise and disinterested stance in the resolution of disputes.¹⁷

Greater reliance on advance judicial review has raised a number of concerns about the relative costs and benefits of relying on courts to pass on the decisions of surrogates for incapacitated patients. Judicial review in such cases is costly in terms of time and expense; it can disrupt the process of providing care for a patient, since medical decisionmaking is evolutionary rather than static; it can create unnecessary strains in the relationship between the surrogate decisionmaker and others, such as the health care providers, who may be forced into the role of formal adversaries in the litigation; and it exposes delicate matters that are usually regarded as private

¹⁶ Nevertheless, arrangements should be made to ensure that the appropriate cases do come before a formal tribunal, as when, for example, the patient expresses a desire for judicial review, or the patient's health needs will require continual decisionmaking on a broad range of issues. Further, it is incumbent upon health care providers to seek review when they believe that a surrogate's decision about treatment fails to reflect the patient's values and goals (to the extent that they are ascertainable) or the patient's best interests.

¹⁷ The argument for judicial review is well stated by Professor Baron. See Charles H. Baron, *Assuring "Detached But Passionate Investigation and Decision": The Role of Guardians Ad Litem in Saikewicz-Type Cases*, 4 AM. J. LAW & MED. 111 (1978); Charles H. Baron, *Medical Paternalism and the Rule of Law: A Reply to Dr. Relman*, 4 AM. J. LAW & MED. 337 (1979). See also *In re Roe*, 421, N.E.2d 40, 51-56 (Mass. 1981); *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 432-35 (1977). The view that judicial review is inappropriate is well stated by Dr. Relman, the editor of the NEW ENGLAND JOURNAL OF MEDICINE. See Arnold S. Relman, *The Saikewicz Decision: A Response to Allen Buchanan's Views on Decision Making for Terminally Ill Incompetents*, 5 AM. J. LAW & MED. 119 (1979).

to the scrutiny of the courtroom and sometimes even to the glare of the communications media.¹⁸

These costs may be justifiable if wiser decisions are made and if patients are provided with additional protection from harm. Frequently, however, it appears that the process of judicial review is merely a formality. Judges may not feel that they are able to add very much to the decisions already reached by those most intimately involved, particularly in cases that are brought simply to obtain judicial sanction for an agreed course of conduct.¹⁹ Rather than being an issue the courts are accustomed to addressing, such as whether the surrogates are appropriate decisionmakers or should be disqualified because they are incompetent or have a conflict of interest, the question typically addressed is whether the treatment chosen is the right one.²⁰ Since this judgment

¹⁸ Buchanan, *supra* note 9, at 105-06.

¹⁹ See, e.g., *In re Nemser*, 51 Misc.2d 616, 273 N.Y.S.2d 624, 629 (S.Ct. 1966), in which a trial court judge to whom a petition for the appointment of a guardian to consent to surgery on an elderly, somewhat incapacitated, but objecting woman, chided the woman's family, the hospital, and the doctors for seeking his imprimatur:

[I]t is apparent that this proceeding was necessitated only because of the current practice of members of the medical profession and their associated hospitals of shifting the burden of their responsibilities to the courts, to determine, in effect, whether doctors should proceed with certain medical procedures definitively found necessary or deemed advisable for the health, welfare, and perhaps even the life of a patient who is either unwilling or unable to consent thereto....

It seems incongruous in light of the physicians' oath that they even seek legal immunity prior to action necessary to sustain life. [H]ow legalistic minded our society has become, and what an ultra-legalistic maze we have created to the extent that society and the individual have become enmeshed and paralyzed by its unrealistic entanglements!

See also William J. Curran, *A Problem of Consent, Kidney Transplantation in Minors*, 34 N.Y.U. L. REV. 891 (1959)

²⁰ See, e.g., *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, 664, *cert. denied*, 429 U.S. 922 (1976):

If a putative decision by Karen to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right of privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice. The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment subject to the qualification hereinafter stated, as to whether she would exercise it in these circumstances. If their conclusion is in the affirmative this decision should be accepted by a society the overwhelming majority of whose members

requires substantial understanding of the patient's medical condition and options, the court may simply defer to the recommendation of the treating physicians. The courts' vaunted disinterest may be closer, in practical effect, to lack of interest.

Institutional review. To provide an alternative that is more responsive to the needs of all parties, "institutional ethics committees"²¹ are increasingly being used.²² Because they are closer to the treatment setting, because their deliberations are informal and typically private (and are usually regarded by the participants as falling within the general rules of medical confidentiality), and because they can reconvene easily or can delegate decisions to a separate subgroup of members, ethics committees may have some marked advantages over judicial review when it comes to decisionmaking that is rapid and sensitive to the issues at hand. Furthermore, testimony presented to the Commission indicated that these committees have had a valuable educational role for professionals.²³

Very little is known, however, about the actual effectiveness of institutional ethics committees, especially in comparison with private, informal mechanisms or with judicial decisionmaking for patients who lack decisionmaking capacity. The composition and functions of existing ethics committees vary substantially from one institution to another. Not enough experience has accumulated to date to know the appropriate and most effective functions and hence the suitable composition of such committees. If their role is to serve primarily as "prognosis committees" to pass on the accuracy of an attending physician's judgment, then committees composed largely of physicians would seem appropriate.²⁴ If the ethics committees are supposed to reach decisions that best reflect the individually defined well-being of patients or the ethicality of decisions, however, it seems doubtful that an exclusively medical group would be suitable. And if the appropriate role of such review

would, we think, in similar circumstances exercise such a choice in the same way for themselves or for those closest to them.

21 The Commission uses the term "institutional ethics committee" rather than "hospital ethics committee" because such committees could well function in other health care institutions such as nursing homes.

22 In the past decade, 5% of large hospitals (that is, those with more than 200 beds) have established such committees. Stuart Youngner, *Hospital Ethics Committees* (1982), Appendix to Commission's forthcoming Report on decisions about life-sustaining treatment.

23 Testimony of Ronald Cranford, M.D., transcript of 21st meeting of the President's Commission (June 10, 1982) at 18, 39.

24 Carole Levine, *Hospital Ethics Committees: A Guarded Prognosis*, 7(3) HASTINGS CTR. REP. 25, 27 (1977); Robert Veatch, *Hospital Ethics Committees: Is There a Role?*, 7(3) HASTINGS CTR. REP. 22, 24 (1977).

bodies should be to determine whether a surrogate decisionmaker is qualified to make medical decisions on a patient's behalf (and to set only outer boundaries on the nature of the decision reached rather than second-guessing the choice), membership should be diverse.

Alternative institutional and private arrangements, formal and informal, deserve careful examination and evaluation. Furthermore, important details, such as means of case referral, range of functions, committee composition, protection of privacy, and legal status, have not been debated, much less resolved. From what little is already known, it seems that ethics committees may be able to take a leading role in formulating and disseminating policy on decisionmaking for incapacitated patients, assisting in the resolution of difficult situations, and protecting the interests of incapacitated patients. Although committees can be reasonably prompt, efficient, sensitive, and private, having many of the decisions about health care for the incapacitated made in an informal manner between surrogate and provider is plainly a desirable objective as well, just as routine decisions for competent patients should be made by patient and provider without any outside intervention. Furthermore, just as judicial review may sometimes be an unnecessarily onerous means of reviewing medical decisions, review by an ethics committee may also sometimes be inappropriate.

The Commission believes there should be various kinds of review mechanisms available. Thus, the Commission recommends that health care institutions not only develop appropriate mechanisms but also encourage and cooperate in comparative evaluations of such approaches.²⁵ The results of these studies will have particular importance for society because one presumed advantage of institutional mechanisms is that they avoid the undesirable aspects of having to turn to more formal means of review. Assurance that any new mechanisms have been well thought out and are appropriate to the task is needed before widespread official sanctions can be expected.

²⁵ To assist in this endeavor, the Commission's forthcoming report on decisions about life-sustaining treatment will provide a more detailed examination of the potentials, liabilities, and reported experience with institutional ethics committees and other mechanisms for ensuring that decisionmaking of high quality occurs.